

PROMOTING POSITIVE SOLUTIONS

QUESTION: *I am a 62-year-old happily married mother of two. I have a history of bulbar polio and have started speech therapy for new swallowing difficulties and problems with vocal endurance. Thus far, I have been able to adjust to every change brought on by post-polio syndrome, but this new change is really hard for me. My speech therapist is instructing me to “conserve my speech.” I am known in my friend and family circle as an outgoing person and a gifted conversationalist. I have been feeling great loss for not being able to be spontaneous verbally. I know the strategies will help in conserving my voice, but I am stuck in grief. Any thoughts?*

Response from Rhoda Olkin, PhD:

Before we deal with potential loss, let us consider what might be happening regarding swallowing and vocal endurance. You mention your speech therapist, and I am not clear what training that implies, whether that person is a medical doctor or someone trained in correcting speech problems. If that person is not an MD, I strongly advise you to seek a consultation with an otolaryngologist, i.e., an ear-nose-throat doctor.

My rationale is twofold. First, to be told to make a major life change such as conserving speech should depend on a thorough evaluation of the problem and any possible remedies, and I would want more than one opinion and at least one of those to come from someone who had examined my apparatus and could give me a cogent explanation of the problem.



Rhoda Olkin, PhD

Dr. Rhoda Olkin is a Distinguished Professor of Clinical Psychology at the California School of Professional Psychology in San Francisco, as well as the Executive Director of the Institute on Disability and Health Psychology.

She is a polio survivor and single mother of two grown children.

Second, it is too easy to ascribe everything to polio.

I went through about five years of thinking I was having swallowing problems – my throat seemed to seize up sometimes when eating, especially when fatigued. I went to an otolaryngologist, who was able to look down my throat (through the nose and down – really really really not as bad as it sounds!) and demonstrate that everything was functioning. She even had me eat dry crackers in front of her and show her what was happening as I swallowed and talked. Turns out nothing was wrong. I therefore learned to relabel swallowing difficulties as anxiety, eat slower and relax a bit more.

Regarding speech, I do lose my voice easily, but I teach, so I certainly cannot talk less. What I do is take short speech breaks about every 15 minutes (I ask students a question), and use a microphone when talking to more than about 10 people, so I don't have to raise my voice to project. I certainly talk as much as I ever did. And yes, sometimes my voice gets raspy and I am quiet for a bit, but by then probably everyone is sick of hearing me anyway! So consider (a) investigating the issue further; (b) using a microphone as needed; (c) going about your life the same as ever.

Okay, so suppose you investigate further and it does become clear that you have to “conserve speech.” As much as I doubt that this is necessary, it is worth considering how to tolerate and manage any major life changes brought by aging and disability, because if it isn't speech, it might be something else. You say you are “stuck in grief.” Are you perhaps thinking this is a necessary stage towards the mythical ideal of acceptance? Because it isn't.

If you are experiencing grief, you need to make sure it is not depression, because depression is very treatable. I do think grief and loss are parts of the process of living with polio, because over time

our abilities change and we have to shed some beloved activities. These activities have to be replaced with equally beloved activities. Speech might take second place to writing, for example. Communication is the goal, and there are myriad ways to communicate these days (email, texting, Facebook, Twitter, etc.). So reducing speech does not equal reduction in communication.

QUESTION: *I am a 79-year-old male who had mild polio. At every annual medical visit, my doctor urges me to manage my stress and feels strongly about meditation. I have tried it and don't like it. Sitting in a room, closing my eyes focusing on my breathing feels boring, and I don't get it. I have read many articles pointing to the health benefits of meditating, but I can't get into it. Is there another approach to stress management that has the same evidence base in terms of effectiveness?*

Response from Stephanie T. Machell, PsyD:

As you've discovered with meditation, it doesn't matter what the evidence base says: the best stress management technique is the one you'll do! It sounds like you've done your research, and so you know that the reason meditation works is because it "resets" your nervous system such that you become less reactive and more reflective.

Being less reactive to stress helps your body because when you react, the sympathetic nervous system pumps out adrenaline. Once the threat is past, the parasympathetic nervous system pumps its own chemicals to clean up the adrenaline. It takes nine times as long for this cleanup to happen – and it results in additional muscle pain and fatigue, which someone with even mild PPS cannot afford.

Meditation is especially effective at accomplishing this.

There is no right or wrong way to meditate and many different techniques. If what turns you off is the silence, solitude and

eyes being closed, you could try keeping your eyes open and doing it in a pleasant place outdoors. Meditating with others in a class at your local hospital or senior center creates a very different experience. Or you could use one of the many available tapes or music.

If meditation itself is the turn-off, there are other things you can do to reduce your stress that have a good evidence base. If you are able to do so, deep breathing takes very little time and can be done any time anywhere. You can learn to do progressive muscle relaxation or visualization exercises from a tape, a book or a class. Autogenic training, which combines a body scan with specific relaxation techniques, appeals to some people.

There are more active approaches to managing stress as well. If you are able to do it, exercise, especially gentle yoga, has been found to be beneficial. Attending religious services, engaging in social activities, doing volunteer work, spending time with friends and loved ones or engaging in a hobby all reduce stress. For those who love animals, research shows spending time interacting with them has health benefits. Writing, especially journaling, is another technique that has a good evidence base. Getting out in nature, even if it's only your own backyard or looking at a beautiful view from the comfort of your car, has also been proven to reduce stress.

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Stephanie T. Machell, PsyD

Dr. Stephanie T. Machell is a psychologist in independent practice in the Greater Boston area and consultant to the International Rehabilitation Center for Polio, Spaulding-Framingham Outpatient Center, Framingham, Massachusetts.

Her father was a polio survivor.

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If none of the above appeals to you, how about laughter? Laughter yoga, where groups of people gather and laugh for an hour (really!), is an up and coming stress reduction technique. Watching funny movies or television shows, listening to comedy or reading humorous books is a stress reduction technique most people enjoy.

I would be remiss if I didn't point out that if your stress levels are extremely high and you are having difficulty managing them on your own, you might want to see a mental health professional for a consultation. In addition to talking about the issues that may be causing your stress, he or she can help you learn effective stress management techniques. ■

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- ◆ Actions taken under this law are not, in any way, legally considered to be suicide.
- ◆ Participating in this program has no effect upon a patient's insurance policy (life, health, accident or annuity).
- ◆ Extensive thorough records are kept on every patient's involvement in an Oregon Death with Dignity Act program and are available to the public.

Deciding on a preferable end-of-life plan can be challenging. Some patients "partner" with other programs as they seek comfort and care in their final months. Not surprisingly, records show that well over 90% of individuals in the Oregon Death with Dignity Act program were enrolled in hospice when they received their lethal prescription or when death came. Many seem to believe that this combination of options lies closest to providing relief from worry about losing their quality of life and dignity as they move nearer to the end. And most choose to meet death in the quiet comfort of their own homes. ■

PHI Elects Two New Board Members

Post-Polio Health International welcomes two new directors who were elected at a recent board meeting: Sandra Loyer of Ann Arbor, Michigan, and Mohammed Yousuf of Fairfax, Virginia.

In addition to teaching, Loyer has more than 30 years' experience in social work in a variety of fields from neurosurgery to spinal cord injury to primary care. Currently she is in private practice and is a military family life consultant to the U.S. Department of Defense. Her community and volunteer activities include board president of the Samaritan Counseling Center and member of the board of the Ann Arbor Center for Independent Living. She holds an AB degree from Ohio University and an MSW degree from the University of Michigan.



Sandra Loyer

"I bring to the board a lot of experience working with people who have had polio and all the knowledge I have learned from them. I have years of experience working with families and have developed an understanding of their needs and ways to help them meet those needs. Over the years, I have listened very carefully to my patients and clients and try hard to understand their particular situation, culture and belief system. I do not believe in a 'one size fits all' approach. My military experiences have expanded my horizons in understanding the human condition. I look forward to both learning from my participation in the PHI board and to actively contributing."

Yousuf is an engineer and disability rights activist whose previous positions include product design and project engineering for Chrysler Corporation and General Motors. Currently he is a research engineer for the U.S. Department of Transportation. He is founder and president of the Equally Able Foundation and co-chair of the ADAMS Accessibility Committee which works to improve inclusion and disability awareness. He holds BS degrees in Electronics & Communication Engineering from Osmania University in India and an MS degree in Computer Engineering from Wayne State University in Michigan.



Mohammed Yousuf

"As a person who has lived with polio most of his life, I know how important PHI could be to those who have been on this journey. I believe that PHI is the only organization that is still working to enhance the lives and independence of polio survivors, and that means a lot to me. Those of us who have lived through difficult times know what independence means, what mobility means. Through PHI, we can make a difference in the lives of people who have had polio and people with disabilities. I hope to make a difference by bringing to the board my personal experiences of dealing with disability, running a disability organization and working in research areas that touch both people with and without disabilities." ■